

Testimony of Kathryn Grigsby

Mr. Chairman, Senator Breaux, members of the Committee and ladies and gentleman, I am honored to be here today.

My name is Kathryn Grigsby. I have served as Executive Director of Hospice of Baton Rouge for 12 years. Hospice of Baton Rouge is a non-profit, independent, United Way hospice provider with an average daily census of 65. We have been meeting the end-of-life care needs since 1984. I also serve as Vice President of the Louisiana Hospice Organization.

My special thanks to Senator Breaux of Louisiana for providing me with this opportunity to testify about issues confronting the terminally ill and their families as they seek a dignified and compassionate closure to their lives.

I am here today to talk about the barriers to hospice care for Medicare eligible individuals in Louisiana. The barriers I will address are not unique to Louisiana.

The modern day American hospice movement began in 1971 in Connecticut. The first freestanding hospice in this nation was the Connecticut Hospice in New Haven and it was founded on the model of care best identified with Dame Cicely Saunders, MD, who opened her now famous Saint Christopher's Hospice in 1967 in Sydenham, England. Her center became the model for comprehensive whole person and family care at the end of life (i.e., spiritual, psychological and medical team-driven care of the terminally ill patient and his/her family).

While hospice began as a grassroots movement in this country, it was institutionalized as part of the Medicare program in 1982. Since enactment, the Benefit has afforded millions of terminally ill Americans and their families an avenue toward a death with dignity.

Simply defined, hospice is a philosophy of care that focuses on the whole person, not on the disease. It is not, as too often is thought, just a place to die. Hospice embraces these principles:

- Supports and cares for persons in the last phases of incurable disease so that they may live as fully and as comfortably as possible;
- Recognizes dying as part of the normal process of living and focuses on maintaining the quality of remaining life;
- Exists in the hope and belief that through appropriate care, and the promotion of a caring community sensitive to their needs, patients and their families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them; and,
- Offers palliative care to terminally ill people and their families without regard for age, gender, nationality, race, creed, sexual orientation, disability, diagnosis, availability of a primary caregiver, or ability to pay. (NHPCO Standards of Hospice Program of Care, 1993)

Far too many patients die without ever being referred for hospice care. This is often the result of an unawareness of hospice and palliative care programs by patients and their families. This lack of knowledge or awareness of compassionate end of life care can lead to tragic and unnecessary pain and suffering - physical, emotional and spiritual -- for the patient and their families.

In order for terminally ill patients and their families to take advantage of hospice care, they must know that a compassionate and caring system exists and is accessible. This knowledge or awareness must come from different levels of information, but the first step in this process is to talk about death.

Only in America does the consumer consider "not dying" an option. There is the perception that there is always one more treatment to consider, one more specialist, usually 200 miles or more away to see. And only in America do health care professionals consider death a failure.

Conversations about our final wishes and how we want to be cared for at the end of life have to take place. It is ironic that we, as a society, celebrate and plan for other life events, like birth or marriage, but refuse to talk about death, until a crisis arises and we are at our worst to make decisions and resolve long standing issues. We, as individuals and families have spent a lifetime arriving at the edge of death, and need and deserve time to address lingering issues that will afford the dying patient, and their families, some better sense of closure and peace.

A recent television series by Bill and Judith Moyers, "On Our On Terms" aired last week. The four programs focused on issues facing dying Americans. In thoughtful and compassionate way, the subjects invited us to witness their struggle with accepting death and how the final months, weeks and days can be made better for the patient and their loved ones. Perhaps this program, and more like it can prompt our on citizens to start talking about death. Maybe when it appears on television, it becomes real for us.

We did a focus group with families of former patients. 90% had never heard of hospice until the physician told the family that hospice had been called. A survey done by the National Hospice Foundation in 1999 found that 80% of those surveyed did not know the meaning of hospice.

Obviously, to avail themselves of this form of care, they must know about it. Education is paramount. We must educate consumers, health care professionals and physicians. Most Americans rely on their health care professionals for information and advice. But, if those very highly educated and trained professionals don't know about, or don't care about quality end-of-life care, then they are failing their patients.

Physician education is essential. Most physicians practicing today have received no training on end-of-life care or communications. According to the AMA, in 1998 only 4 out of 126 medical schools in the U.S. had any formal training available on hospice care, death and dying, palliative care or end-of-life care. Other areas of medicine receive intensive training, but end-of-life care is a glaring example of an area needing more attention.

Once they know about hospice care, physicians must feel free to refer appropriate patients to hospice care. Unfortunately, many physicians are reluctant to refer patients to hospice. The activities of Operation Restore Trust and the Office of the Inspector General have exacerbated the problem resulting in even later referrals. Misperceptions about the actual eligibility requirements for the Medicare Hospice benefit are another problem confronting access to hospice. Congress, when they enacted the Benefit in 1982, recognized that predicting death was an inexact science and never intended the prognoses of patients to be a hard and fast requirement. Rather, the six month period was intended to be a guidepost, ensuring Americans access to end of life care, not some limiting factor.

As an example of this misperception, let me read you comments from one of our local physician's. These are direct quotes from our Physician's Order Sheet that we require the attending physicians to sign. "I do not authorize death in six months. This is not my opinion. I appreciate your help with my patient. Please do not ask me to predict death. If I do this then (at the end of six months) of six months, I will have to kill the patient, which I can't do."

There are no incentives for physicians to discontinue treatment. I believe some physicians continue to provide aggressive treatment when hospice care would be in the patient's best interest and more

economical as well.

Recently we received a referral on a patient with a non-cancer diagnosis. The diagnosis was COPD (chronic obstructive pulmonary disease). The history and physical exam stated the patient had a history of prostate cancer, skin cancer, a laryngectomy with tracheostomy (cancer related), cervical soft tissue mass suspicious for recurrent tumor and frequent pneumonia.

The patient had been hospitalized the week before to be "worked up for possible myopathy or neuropathy." According to the wife, the goal was to get him into a rehabilitation unit.

The patient was clearly in the final stages of life. I explained our services to his wife and three adult children and said we could admit him whenever they made their decision. The wife stated that she had heard of hospice but thought it was a place.

Three days later he died in that same hospital room, a week before he was admitted to the hospital to be evaluated for the rehabilitation unit.

This man was clearly hospice appropriate. He was not a candidate for the rehabilitation unit, but he continued to receive "aggressive treatment" until days before his death.

This is not an isolated incident.

Our median length of stay is 20 days. Nationally the median length of stay is 29 days. This year half of our patients have died within 20 days of admission. 16% of the patients referred to Hospice of Baton Rouge die before we can make a visit.

Let me convey another story and tell you that these are not isolated incidents. They are routine, every day occurrences in hospices, large and small, across the country.

It was mid-June and a typical frantic Friday at HBR. The voice on the phone is that of a local physician whom I have known since high school. He said, "Kathryn, I need your help. My dad is 82. He has been in a coma for 3 weeks. He has a living will. He signed advanced directives upon entering the hospital and we want to take him home. "

Then his voice began to crack. " I love my dad. I would never do anything to harm him. I only want to do what he asked me to do." There was a long pause.

He continued. " Mom wants to take Dad home. He has always told us he wants to die at home, but his doctor said that I might as well take a gun and put it to his head if we take him home without inserting a feeding tube. The neurologist has told us there is no hope for any recovery."

"I need your help. Please tell me what to do. My father's physician is a colleague of mine. I work with him all the time."

We discussed the situation. The dad had made his final wishes clear and all members of the family wanted to honor his wishes. I suggested that the family find another physician, and they did. With the help of HBR, Mr. Jones went home and died peacefully in his own bed, surrounded by his wife and children several days later.

Congress recognized the need for this kind of care in 1982 when it enacted the Medicare Hospice

Benefit to provide compassionate and specialized care for the dying. While millions of terminally ill older Americans and their families have had the opportunity to experience more comfortable and dignified deaths, the reimbursement rate has not kept pace with the changes in end of life care -- especially due to increasing costs of prescription drugs and outpatient therapies, as well as decreasing lengths of service. Medicare Hospice Benefit reimbursement rates need to be increased if hospice programs are to continue to provide high quality care and related services that our nation's most vulnerable population needs and deserves.

Once a patient chooses hospice care, he or she is afforded the per diem reimbursement as the only Medicare payment for all costs related to the terminal illness, including physicians' oversight services, nursing care, counseling, spiritual support, bereavement counseling, medical appliances, drugs, home health aides, homemaker services, physical and occupational therapies, dietary advice, and volunteer assistance. An interdisciplinary team provides medical, social, psychological, emotional and spiritual services to the hospice patients and their loved ones.

In 1982, when hospice care was added as a Medicare benefit, the routine home care rate was set at \$41.46 per day. When the benefit was established, the reimbursement rate did not include an annual inflationary update. Rather, Congress provided specific rate increases and later tied the hospice reimbursement rate to the hospital market basket to provide for inflation. Unfortunately, the rate has not kept pace with the growing cost of delivering care to terminally ill Medicare beneficiaries. The fiscal year 2000 routine home care rate, at which more than 95% of all Medicare hospice patients are billed, is \$98.96.

Unfortunately, the current reimbursement rate does not begin to cover the expenses incurred in delivering compassionate and specialized care to dying Americans. An interim report of an ongoing hospice cost study by Milliman & Robertson (M&R) states, *"the trend is clear that Medicare hospice per diem payments do not cover the costs of hospice care and result in significant financial losses to hospice programs throughout the country."* M&R notes several other factors driving the losses that hospices are experiencing today.

According to the M&R study, *"new technology, including breakthrough therapies and prescription drugs, has increased hospice costs far beyond Medicare's annual market basket update. For example, when Medicare set hospice payments in the 1980s, prescription drugs for hospice patients represented about \$1 of the per diem reimbursement rate. M&R noted that these costs increased to approximately \$16 per day by the late 1990s (an increase of about 1,500%)."* Drug costs have skyrocketed, making pain relief and symptom management, cornerstones of hospice care, much more expensive. Many of the most effective and widely used drugs for relief of cancer patients' discomfort are shockingly expensive. Duragesic, one of the most commonly used pain relievers for cancer patients, can cost up to \$36 per dose. Zofran, an effective anti-nausea drug, costs almost \$100 per day - exceeding the entire routine home care rate paid by Medicare to the hospice provider.

We had a patient whose blood products and transfusion costs alone were in excess of \$25,000.00. Our total reimbursement from Medicare for all of her care was \$9,960.63.

But escalating drug costs are not the only problem facing hospices.

For a variety of reasons, more and more patients are being admitted to hospice programs very late in their illness, when they require a greater intensity and variety of services. Their hospice care needs, including pain and symptom management and personal support, are often the greatest in the first few days following admission and in the final days and hours before death.

The Medicare Hospice Benefit was designed to balance the high costs associated with admission and the period immediately preceding death with the somewhat lower costs associated with periods of non-crisis care. However, the median length of service for hospice patients has fallen rapidly in recent years leaving fewer "non-crisis" days. The very short lengths of service and advances in clinical practices, both significant cost factors, were not anticipated at the time the original rate structure was formulated. These added financial pressures are having a devastating impact on hospices.

In the longer-term, Congress needs to undertake a review of the assumptions under which hospice reimbursements are made. New drug treatment modalities and types of medications have come to establish new areas of medical practice, and we need to have them available to the hospice practitioner and other health professionals. We in hospice know how to alleviate pain and control symptoms. But, far too often, the skyrocketing cost of such treatments force us to seek other less expensive and perhaps less effective alternatives. In fact, the vast majority of the nation's hospices resort to public fundraising to supplement their operational and capital costs. Within the context of the Medicare Hospice Benefit, we need a dramatic increase in our reimbursement rates. We need these changes now.

Routine regulatory reviews and investigations are having a substantial, and presumably unintended, adverse impact on end of life care and access to hospice. Such reviews should be undertaken with the goal of assuring quality patient care and compliance to the intent of the regulations. Unfortunately, many of the regulatory actions deal with technical interpretations of the regulations and they are neither focused on nor related to good patient care. The investigations, on the other hand, may have the unintended effect of creating a chilling environment for attending physicians and hospice providers, fearful of government review and possible prosecution.

According to the Medicare Payment Advisory Commission, "[t]he gap between the care now given to dying beneficiaries and ideal care is wider than in probably any other area of medicine... closing this gap should be one of the highest priorities of the Medicare program."

By adopting the Medicare Hospice Benefit in 1982, Congress took an important step in changing a deeply embedded aspect of our culture, one that denies the inevitability of death and ignores the value of the end of life. We continue to believe today, that hospice care is our best response to caring for people at the end of life.

Yet, there are any numbers of obstacles to ensuring access to hospice care for individuals in this country. In fact, we are witnessing an alarming decline in the lengths of service for hospice patients, which is turning hospice into a "brink of death" benefit. The National Hospice and Palliative Care Organization's data show that the number of hospice patients has steadily increased, totaling over 700,000 individuals last year. In 1998, their median length of service fell to just 25 days, which represents a 26% decline since 1992. This means that over one half of all hospice patients - 50% of men, women and children in hospice care -- die within one month of admission. This is happening at a time when access to hospice care should be deepening and broadening, not contracting.

According to a study done by Lewin-VHI in 1995, for every \$1.00 spent on the Hospice Medicare Benefit HCFA saves a \$1.52. "The 1995 study also showed that in the last year of life, hospice patients incurred \$2,737.00 less in costs than those not on the Medicare Hospice Benefit. These savings totaled \$3,192.00 in the last month of life because hospice home-care days often substitute for expensive hospitalizations."

All Americans should have hospice available to them, but reaching rural patients and families is difficult. Smaller hospice programs are hindered by higher costs and lack of economies of scale. At the

same time, existing reimbursement rates do not take into consideration distance or drive times, patients in rural areas are frequently denied hospice. With the current reimbursement rate, which is only 80% of the routine home care rate, hospices cannot afford to provide services to patients who live long distances from the office. The rural "floor" needs to be raised so that everyone has a chance to have a dignified and comfortable death.

We need to find economical ways to provide hospice care to individuals without able or available caregivers. Imagine an 86 year-old man trying to care for his 83 year-old wife. As a contemporary of mine said recently, "If my mother needs hospice, I will have to make a decision whether to put her in a nursing home or leave my job. Financially we cannot afford to pay sitters." Today there are 40 million senior citizens. How many of them can afford to pay for sitter assistance?

And it is not just our older citizens who need hospice care. Let me read you another letter from one of our families.

We would like to let you know how grateful we are... I never would have believed seven years ago when my child was born she would become terminally ill. It was an incredibly horrible experience to watch her die after a two-year battle with a brain tumor. She passed away in her room, in her bed, in our arms. Without the support of Hospice of Baton Rouge, I don't know how we could have managed.... I think people usually associate hospice with older people. It is important to know that babies, children and their families need hospice, too...."

Every terminally ill American should have access to hospice care. There are many barriers but I am confident that there are as many solutions. With your help we can find ways to provide hospice care to the young and old alike in America.

Thank you.